

**Update on SACGHS Efforts on Genetic Discrimination**  
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DR. TUCKSON: Well, with that, let's turn then to Agnes and to Cindy, who will take us through this very important first part of our meeting, with an update on genetic discrimination.

MS. MASNY: As Reed had mentioned, there has been a lot of activity from the task force, as well as legislative action that's been happening, so we wanted to update you on all these activities. Cindy and I will be splitting the presentation.

Just as a recap, the genetic discrimination has been noted as one of the highest priority categories for our committee's work. In the past already two letters were sent to Secretary Thompson supporting federal genetic non-discrimination legislation and Senate 1053 in particular. The committee, in our October session, held a specific session on genetic discrimination to gather the public's perspective on the magnitude, the scope, and the impact of genetic discrimination, and most specifically we tried to address the issue of the fear of genetic discrimination in society. We received testimony from members of the public, health care providers, and other stakeholders.

So what we're going to be presenting today is some of the legislative activity that has taken place to give you an update on the report that we are to put together that's to go to the Secretary, and as Dr. McCabe had indicated at our last meeting, we wanted to make it about telephone book size, and then to update you on the fact-finding efforts that have been going on with the stakeholders, and this is the specific part that Cindy will present. Then as a committee we will discuss what steps we would like to take next.

So these are the members that have been on the Genetic Discrimination Task Force, and also I just wanted to point out the work of Amanda Sarata and Sarah Carr, who have been working extensively behind the scenes, along with all the task force members.

So for the legislative update, as you have seen in your packets that you got, your briefing books, the Genetic Information Non-Discrimination Act of 2005, Senate 306, has been introduced earlier this month. It was sponsored by Senator Snowe, co-sponsored by Senators Frist, Gregg, Kennedy, Enzi, Jeffords, Dodd, Harkin, and you can see the rest there that are on the slides. This bill is nearly identical to the one that was passed by the Senate in 2003. So the bill prohibits group health plans and health insurers from denying coverage to a healthy individual or charging a person higher premiums based solely on genetic predisposition to developing a future disease. It also bars employers from using genetic information when making hiring, firing, job placement, or promotion decisions.

So the bill actually has passed the Health, Education, Labor and Pension Committee earlier this month and then was debated on the Senate Floor on February 16th. Although, with all the work that has been done, we can't take credit for everything, but just to mention that there were several references from the work of the committee and its support for genetic non-discrimination legislation, as well as Secretary Tommy Thompson's response to the committee's letters that he has received. Specifically, Senator Enzi mentioned testimony of our last meeting and the testimony of Heidi Williams and Tonia Phillips, and Senator Kennedy mentioned the testimony of Heidi Williams and Phil Hardt.

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So almost simultaneously to that particular action, the Executive Office of the President from the Office of Management and Budget gave out a statement of administration policy on February 16th. That administrative statement was passed out in your books for today, but just to highlight one of the aspects of it, and that is the administration favors enactment of legislation to prohibit the improper use of genetic information in health insurance and employment. The administration supports the Senate passage of 306 as reported. The concern about unwarranted use of genetic information threatens access to utilization of existing genetic tests, as well as the ability to conduct further research. The administration wants to work with the Congress to make genetic discrimination illegal and provide individuals with fair and reasonable protections against improper use of their genetic information. So this has all been very, very positive, and we've been very excited about this movement itself.

Then the next day after the administration policy was issued, the bill was unanimously passed by the Senate.

As far as the House goes, no bills have been introduced to date on genetic discrimination. In the last Congress, even though the Senate passed 1053, several bills were introduced in the House but none of them moved forward. The committee is hopeful that the Senate bill is going to be introduced very soon in the House.

As far as the update on our report goes to the Secretary, at the conclusion of our public testimony and the roundtable discussions that were held in October 2004, the committee recommended that we take several actions, and one of them, the first, was to compile the testimony that we heard, and the public comments that were received by the committee, and relevant scientific articles, to submit them to the Secretary. This was what I was referring to, our telephone book sized report to the Secretary.

Then to gather information from stakeholders, and to facilitate a meeting of the stakeholders. Some of these stakeholders were the Genetic Information Non-Discrimination and Employment Coalition. That's GINE. AHIP is the America's Health Insurance Plans, the Chamber, and the Coalition for Genetic Fairness. We did receive testimony from one of the groups, but we wanted to have further input from all of the stakeholders to be able to get perspectives on all of the issues that they had.

Then lastly, our third job was to facilitate an analysis with the Department of Justice and the Equal Employment Opportunities Commission of the current law that we had in terms of protecting the public against genetic discrimination.

So here's what has been happening. The task force held a call in late November to further develop a work plan and carry through on the outcomes that we had decided upon at the October meeting. The task force found that the broad testimony received from the providers and other stakeholders pointed out the range of perspectives on this issue and really did need a deeper analysis. So the task force worked out a three-part structure for the report to the Secretary.

The first of them was, of course, the public comments. Prior to the October meeting, the committee had solicited the public comments and received a significant number of responses in addition to the 14 testimonies and public comments received during the October sessions. All of these comments have been compiled in a document. The task force also concluded that the testimony of the seven patients that presented to us was so compelling that we should take excerpts and highlight them in a DVD. So what you have in your briefing book is you'll see that

you actually have the script for that DVD, and that's something that we would like to discuss further in our discussion points.

Secondly, the second component in the report to the Secretary will be the stakeholder analysis, and this is looking at all the stakeholders' positions, their points of agreement and disagreement, and where consensus possibly can be reached. Cindy Berry will be going into more detail on the fact-finding from the stakeholders' meetings.

Then the third component that we were given to work on was the legal analysis, and that is actually being prepared by a committee, our committee staff, with technical assistance from the Office of Civil Rights, and the Centers for Medicare and Medicaid Services, the Department of Justice, Department of Labor, and the Equal Employment Opportunities Commission. All of this work is actually to help us to inform the debate about the accuracy and completeness of the current legislation that we have.

Now I'm going to turn it over to Cindy so that she'll give us an update on the fact-finding from all of the stakeholders' opinions.

MS. BERRY: Thank you, Agnes, our fearless leader. Fact finding. This component of the report really centers around the different perspectives and opinions of the variety of stakeholders, and we wanted to consult with as many groups as possible to really get a good feel for what their view is on genetic non-discrimination. We know in Washington, while this issue is a high priority for this committee, there are a variety of viewpoints. People come at this issue from different perspectives, from the employer perspective, from the health insurer perspective, from the consumer perspective, and we really wanted to get a very deep understanding of these different views and gather much more detailed information that could be compiled into the report.

So we conferred with the U.S. Chamber of Commerce, America's Health Insurance Plans, and the Coalition for Genetic Fairness, and we'll report to you on each of those conversations. Starting first with AHIP, America's Health Insurance Plans, they shared a copy with us of a letter that they sent on February 22nd to Chairman Boehner of the House Education and Workforce Committee, and Chairman Barton of the Energy and Commerce Committee. This letter is in your table folders, and it outlines in greater detail AHIP's position on genetic non-discrimination legislation.

You have the letter before you, but I'll highlight just a few of the key points. AHIP expresses opposition to genetic discrimination, stating that consumers should be protected from discrimination based on genetic information. In the letter AHIP also expresses support for protections established by HIPAA, the Health Insurance Portability and Accountability Act, and indicates that S. 306, the bill that just passed the Senate, would not undermine important quality improvement and disease management programs. That was a positive statement with regard to that bill.

The letter goes on to state that AHIP is committed to continuing to play a constructive role in the ongoing debate on this issue and urges Congress to address the issue at a deliberate and thoughtful pace.

Next we turn to the U.S. Chamber of Commerce, and as you all know, the Chamber is a large business federation that represents millions of businesses, state and local chambers of commerce, and business associations across the country. Their mission is to advance human progress through an economic, political and social system based on individual freedom, incentive, initiative, opportunity, and responsibility. We talked to the Chamber about their position on

genetic discrimination, and they outlined for us some general points, and then more specific issues with regard to the legislation at hand.

The Chamber believes that employers should be able to make decisions based on genetic discrimination in cases where the employee is an imminent threat to the workplace or the employee, and they gave us an example. That example would be an employer needing to reassign an employee working with a particular hazardous material if the employee has a genetic predisposition that makes it likely that the hazardous material poses a greater threat to the employee. So that is one example where the Chamber said they probably need to have, from the employer's perspective, a certain amount of flexibility to protect even members of their own workforce.

The general concerns that the Chamber outlined for us are listed on the screen there. Basically, there is no record of employers discriminating, or no widespread discrimination in the workplace that's been documented, so they feel that the goal of any legislation should be focused on reducing employee fear of potential discrimination. They are also concerned about the possibility of increased liability and frivolous lawsuits. Thirdly, the Chamber contends that current law does provide appropriate protection of confidentiality of medical information, including genetic information.

The Chamber outlined for us specific concerns as well, in addition to the more general concerns that we just went over. First, they feel that damage provisions in the law, in the statute, should be limited to equitable relief. They believe that one federal standard should apply and should preempt different state and local laws. The definition of "family" should be limited. Lastly, they feel that the study commission should be truly independent and not housed within the EEOC.

Next we spoke to the GINE Coalition, and this is a group of employers, trade associations and professional organizations. They have on their steering committee the Chamber, the Society for Human Resource Management, NAM, HR Policy Association, College and University Professionals, and the Association for Human Resources. We asked them about their position on genetic non-discrimination legislation.

They contend that there is no appreciable evidence of genetic discrimination in the workplace. Their focus is on employment discrimination, not health insurance discrimination, and they too have concerns about unintended consequences, unnecessary regulation, and excessive litigation.

The Coalition for Genetic Fairness strongly supports federal genetic non-discrimination legislation, and their mission is to educate congressional policymakers and staff about the importance of implementing legal protections in this area and passing non-discrimination legislation at the federal level.

I won't go through all the members of their executive committee. They're up there on the slide. But they are looking to broaden their existing membership to include patient groups that address not only rare diseases but also common complex diseases such as cancer and heart disease. They're looking to expand the membership in the provider community to include umbrella provider organizations. They are currently working, of course, with the American Academy of Pediatrics, but they want to go beyond that specialty society and focus on broader groups as well, and they're looking to expand into industry so that the business community is represented in this coalition as well.

Their position on the genetic non-discrimination legislation is that it is important because of the need to have predictability for consumers and providers. They feel that the lack of federal legislation in this area creates an unfriendly climate for companies trying to develop new innovations in this area, and they feel that patients and providers must be willing to participate in research supporting the development of new products, and that the lack of federal legislation thwarts that goal. They feel that employers would benefit from predictability in this area, and they are not convinced that current law provides sufficient clarity or protection.

They also contend that the remedies available under existing laws are murky and not necessarily limited as they are under S. 306. So they actually feel that the federal legislation as portrayed in S. 306, the bill that just passed the Senate, would provide a greater deal of clarity for employers, as well as for consumers. They have been embarking on a variety of legislative efforts. They've been very supportive of S. 306. Senate Majority Leader Frist and the Health Committee Chairman Enzi are advocating for this bill, and the Coalition's efforts have been an effort to support passage of this bill, not only in the Senate but now as the action shifts over to the House.

They are in discussion with a number of key senior House republicans regarding introduction of the Senate bill. I think their hope is that a republican will step to the plate and serve as the lead sponsor, along with Representative Slaughter, who was the Congresswoman who was the lead in previous Congresses on genetic non-discrimination legislation. I think their goal also, as it was articulated to us, is to have the Senate bill introduced in the House as opposed to having a different House version. The idea would be that this would streamline passage of the legislation so that you wouldn't have competing versions and then have to have a prolonged conference.

They are going to be working with the House Energy and Commerce Committee, the Education and Workforce Committee, and I do believe also the Ways and Means Committee, unless someone has figured out a way to draft a bill to avoid that committee's jurisdiction. But that was one of the difficulties in the last session of Congress. When a bill is referred to three different committees, it's kind of hard to get it going through the entire process.

I will stop here and Agnes, I believe, will lead us in a discussion of next steps.

MS. MASNY: First, I guess before we go on with any of our discussion on the next steps is to hear if we have any questions from the committee members about the work that has been going on, if you'd like us to further elucidate what was presented.

Ed?

DR. McCABE: Yes, I just would like to commend the task force on your excellent work. Clearly, you've been doing a lot of work on this very important effort, and I hope that that work leads to greater success in the House this year than we've had in the past. Thank you.

MS. MASNY: Hunt?

DR. WILLARD: Just a question, and you may or may not be able to respond, about the letter from America's Health Insurance Plans. I'm torn in trying to read between the lines whether this is actually a generally supportive letter on their part or whether, when we read phrases like "It's critically important for Congress to take time to consider the implications," whether in fact they're more in favor of a stalling and a slowing down the process in the interest of obtaining further information but clearly not in the interest of driving this to passage in this session. Any insights from the task force?

DR. TUCKSON: I've been sort of on some of these calls, and let me just make first of all a general observation. I want to echo Ed's sentiment to the committee, and also to the staff who have been working this. There have been some very intense, I think very specific and detailed conversations with each of the stakeholders that you've heard there. I think one of the things that's hard to gauge in the PowerPoint slides is a sense of the subtleties and the nuances of where different constituencies are really coming from.

There's no question, at least from my listening to those conversations, the sense that people really do, on all sides of this issue, understand the need for moving legislation forward. Where I think people are really concerned, as the PowerPoint indicated, is around the unintended consequences, and particularly the legal exposures, and that's just another issue. If there was some way of divorcing, of having the conversation about the legal stuff separate from some of the genetics stuff, this thing would be a lot easier. It's not as if you can sense from anybody involved in this process that they don't want to see the fear of discrimination gone away. I mean, I think people get that.

The issue is what do you do about the unintended? So that's the subtlety. The way I read the letter from AHIP, and I'm not in a position to speak for them but just in listening to the conversation with them, it seemed to be that what they are looking at are the same things that our committee is looking at doing, which is the legal analysis around the adequacy of current protections in that same kind of trying to get clearer about what things sort of exist now.

I think the other area that AHIP seemed to be emphasizing was just making sure again that the use of information in service to the coordination of care for people was not violated. Other than that, Hunt, I can't tell, but I did not, at least as one person, get the sense that they were putting that in as a stalling tactic. That was not what came through at all, but others may see it differently.

DR. TELFAIR: Just a quick question. In listening to the presentation, I'll be learning more about this, but in your conversations with them, did you get a sense of -- well, a lot of times when you have this kind of discussion with them, they sort of recommend this is where we think it should go, but this is what we believe will be the case. I was wondering do you believe it to be the case in terms of will you see a change? Is this realistic? Will it happen? What did you get the sense from the discussions where people were with this in terms of their hopefulness that next steps will occur and be effective in the direction that they would like to see?

I ask that question because that's really important when you try to make decisions about recommendations, because you need to get a sense of where people believe it's going to go.

MS. MASNY: Just for the committee in general as to where --

DR. TELFAIR: Yes, for the committee in general. Dr. Tuckson said there are things you don't see.

MS. MASNY: Well, I think that's one of the reasons why some of the next steps that we have up there is that one of the things we wanted to do was actually move ahead with the report to the Secretary, but actually divide it into three separate components. Since we already have compiled the testimony from the public, that would be something that we already have that we could move forward with if we get the approval from the committee for the script for the DVD. Then to do some further investigation with the stakeholders so that we clearly present the perspectives of all of the stakeholders that are involved, and then the third component, of course, would be the

legislation, so that once we get the analysis, that might even help with the perspective from the stakeholders as well.

But we don't have that completely finished, the legal analysis, as of yet, nor a complete in-depth look into all the perspectives or have that compiled because things are kind of changing all the time with the legislation.

DR. TUCKSON: I think, Joe, the other thing I would say, I guess, is that the slides, although these issues are nuanced and subtle, they're fairly specific also in terms of what those words say there. Again, I'm being very careful here, but what we did see in those conversations was a willingness I think on the part of all the constituencies that were consulted to engage in pretty serious discussion and to try very hard to get to a place of some agreement on these issues. So people are working these issues. As a result, I think the only thing that we can predict reasonably is that we will not know any more until legislation gets introduced in the House, and that people will then react very specifically to very specific parts of that legislation, and they've been very clear as to where their concerns will be.

As a result of that, Joe, I think what your question is getting at, therefore what do we understand to be reasonable next steps, I would say that in terms of trying to predict our ability to get any more consensus than you see on this piece of paper, I doubt there's anything else that we can do until the specific legislation is introduced in the House. I think that's what you're trying to get at.

MS. MASNY: Francis?

DR. COLLINS: I also want to commend the task force for the work you've done to track this issue, and for all of the consultations you're doing which are critical with really important groups that are going to have a big impact on what happens.

I confess that when I read words like, well, we need to approach this at a deliberative and thoughtful pace, that it does seem like we've kind of been doing that. If you look back at the record of what's gone on, it has been 10 years now since an article was published in Science magazine advocating for the need for federal legislation to protect against genetic discrimination. In health insurance, two years later, a similar article advocating about the workplace. Both of those articles not only pointing out the need, giving examples where discrimination was occurring, albeit not a lot of them, and also making specific recommendations about definitions and the kind of language that would be needed in effective legislation, many of which are reflected in this current bill, S. 306.

So it does seem like a fairly deliberate and thoughtful pace has been adhered to. Just the same, we still, I think, are facing an uncertain time here. I looked back, or my staff did, at the history of S. 1053, which you will remember passed the United States Senate 95 to nothing, a unanimous vote in October of 2003, and yet 12 months went by without any action being taken on that bill, not even being referred to committee. That was the only bill in the 108th Congress in a two-year session that passed the Senate unanimously and was never assigned to a committee in the House.

So that indicates to you that there's something going on here in terms of resistance, and it's not going to be trivial to overcome that. Just the same, I think we have a real opportunity this year to revisit the question, and I agree with what Reed said about the willingness of the various parties to get engaged on the specifics of the details once there is a bill introduced in the House to be discussed, and I do think timing is everything. This momentum to try to get this considered in the House is really important and not to allow that to linger on.

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I do also think it's an ideal moment for the new Secretary of Health and Human Services to be quickly engaged on this issue. You reported on the statement of administration policy. It's very clear where the Bush administration stands on this, but the personal role that the Secretary takes in this could turn out to be pretty important, and whatever you decide to do, then, about next steps, I would urge you to try to do it quickly.

MS. MASNY: Thank you, Francis.

Emily?

DR. WINN-DEEN: So I guess, sort of on that same vein, one of the things that I would very clearly like to understand, and I don't know if you have the information, Agnes, or if staff does, what is the timing that we have to do before this once again just falls off as unacted on? We should work with that kind of schedule in mind. So I would urge us to try and get at least Part 1 finished today to whatever point we feel it's ready and send it on so that we don't have a lot of stuff stuck within our own committee, and then to move forward with the other two parts as quickly as we can.

MS. MASNY: So your question would be what would the timing in the House be to have a bill presented before we're going to lose the opportunity?

DR. WINN-DEEN: Before it just falls off, like 1053 did. So it wasn't acted on in a certain time period, and then it just disappears. I just personally don't know what that is. Is it this fall? Is it a two-year period?

MS. BERRY: It's a two-year period. We just started this 109th Congress, so now we don't have a full two years. Obviously, if a bill is introduced one month before the session is supposed to end, chances will be pretty bleak as far as passage goes. But we do have a little bit of time. That doesn't mean that we shouldn't necessarily take a thoughtful, deliberate pace, but we do have some time before a House bill really needs to be introduced. Keep in mind that if it does get referred to three different committees, as the last bill in the House did, that will take an enormous amount of time for hearings and markups for it to go through the regular process.

The only other way to pry it loose, and this was tried the last time unsuccessfully, but it certainly can be attempted again, is if the Senate bill is introduced in the House in an identical version and they bypass the committee process and take it directly to the House floor. That's a rather extraordinary thing to do. It's certainly been done, but it's not the kind of thing the committee chairmen like to go along with because they do like to exercise their jurisdiction over these things, and it's an important enough issue that I don't imagine that the three committee chairmen would willingly give up their jurisdiction to allow a bill like this to go directly to the floor. That's sort of a tactic of last resort.

So I would guess within this first year it would be ideal to have a bill introduced in the House to give us another year for the regular House process to go through, and possibly result in floor action.

MS. MASNY: Ed?

DR. McCABE: With that, I would urge us to move with dispatch here in terms of the report that's been proposed, and especially the DVD. When I read the script of the DVD, it really brings up the passion of the individuals who were involved, talking about how they had to hide their genetic

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information, how they delayed testing for 10 years because of concern about this. Twice I saw in your slides statements that this isn't a problem, there's no reason to worry about it because it's not really a problem, and yet we know it is a problem. I think I admonished the genetics community to stop publishing statements that genetic discrimination is not a problem. Those papers have been skewed, they were poorly performed, and they've done a disservice to the entire American people.

We've got to get that telephone book out there so that that can no longer be used as an excuse: No problem, therefore no need for a remedy.

DR. TUCKSON: Let me just make one other quick comment to Ed's point. Again, I really do understand how hard it is to follow this. As the chairman, I'm always trying to find ways to get the consensus and trying to find where the common ground is and making sure that we don't lose at least sight of where there are opportunities to bring constituencies together. So I'm always going to try to find those silver clouds.

If you look on the handouts on the slides on page 3 under the Chamber's position on genetic discrimination, the second bullet, because Ed sort of said it's important, does not believe employers are currently engaging in genetic discrimination, but then they added a comma and a phrase, "though it does recognize that fear of potential discrimination may warrant a legislative solution."

This is again where I want to make sure that the nuances of the words are noticed by the committee. This is an addendum that they made after the end of our discussions with them. So that phrase is important, and again I just want you to not fly by that phrase. What it ultimately means when the bill goes to the House, I can't predict. But I think Ed's point is important, but notice that that is a recognition of something there. It's a subtle point, but it's a very important point. Is it determinant? I don't know, and I don't want to overplay it, Ed. But I just want to highlight that they are looking at these issues.

MS. MASNY: Ed, do you have a follow-up comment?

DR. McCABE: Just to follow up, I think that does leave the door open a crack, or at least say that we may agree to disagree but allow things to move forward. I think we need to take advantage of that. I also think we need to point out to Secretary Leavitt, and I'm sure you will do this when you brief the Secretary, that this is a civil right. We're seeing a violation of individuals' civil rights, and I think that we also need to recognize that what they're concerned about is the litigation, the remedies as they put it.

I've said this before. If, in fact, genetic discrimination is not occurring, then what is the fear of remedy? So if they do not feel that anybody is really doing this and it's simply the fear of the American people, then it would seem to me that they should be willing to support this legislation because, in fact, there is no fear of litigation if they really firmly believe that no one is discriminating.

MS. MASNY: We'll have Barbara, Emily, and then Kevin. I mean Debra.

DR. LEONARD: So 1053 got stalled by not being introduced into the House, and we have the three committee chairs. Are the three committee chairs the same as they were in the last Congress, or have they changed?

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MS. BERRY: They changed a little bit last year. Chairman Barton was relatively new towards the end of the last congressional session to the Energy and Commerce Committee chairmanship. It was Mr. Tauzin before he left Congress, and then Mr. Barton took the chairmanship. Ways and Means is the same, and Education and Workforce is the same.

DR. LEONARD: So there are several steps in the process. One is just simply getting a bill or the bill that passed the Senate this time introduced. How do we do that? That wasn't able to be accomplished last time. So how does that get influenced to happen? And then once it is introduced, can we encourage the Secretary to distribute the report to him to the committee chairs as well so that they have this phone book sized information emphasizing that genetic discrimination is happening?

But I'm very concerned about that first step. How do you get a bill introduced, and what are the barriers to that happening? Do we know that yet? Because basically we're talking about when it's introduced what we do. But if we don't get past that introduction step, it's not going to happen.

DR. McCABE: Well, I think that Sharon Terry's group is probably one of the most effective ways of getting it introduced, and that is getting a large coalition together and maybe taking their information straight to the Congress. I mean, if this is not a problem, then there should be nobody standing on the steps of the Congress when they deliver their message. But my guess is that they could get a very large group of people –

DR. TUCKSON: Let me ask the staff if they can help us. We are well aware, I believe, and I want to make sure, that the advocacy coalition is moving with some deliberate speed to use their considerable opportunities to get something in place. So I think, Debra, you're asking a couple of questions here, if I understand you. One is, is there a role that we can play in that regard? Of course, as Sarah said up front, we're advisory to the Secretary, but there is something in play right now to make that happen. Can we just ask for what we know about that?

MS. CARR: My understanding from the conversations we had with the Coalition for Genetic Fairness is that they are working hard in the House and talking to members of Congress on both sides of the aisle to try to find a sponsor of the Senate bill, and they are interested in seeing one bill introduced in that chamber, and that bill is the Senate bill. So it seems that the advocates for this legislation are very hard at work on finding a sponsor of the Senate bill, and they sound quite optimistic. Maybe it will happen. I'm not sure if anybody from the Coalition is here.

Jo Boughman, our good friend Jo Boughman. Would you like to come and tell us –

DR. BOUGHMAN: I'm a member of the steering committee of the Coalition of Genetic Fairness. Sharon Terry was not able to be here today because she has her own board meeting.

Sarah and others have, in fact, represented the activities of the Coalition I think very fairly. There have been many meetings on the Hill with staff members and Congressmen on both sides of the aisle, as you pointed out, Sarah, and we are working very hard and as quickly as possible to utilize this momentum. I think it's fair to say that we do have some optimism. We hope it is not naive optimism. But we certainly have a lot of energy moving in that direction.

DR. TUCKSON: I did get an email last night from Sharon, who is probably even at her board meeting monitoring this online. So I expect to probably get a line in a couple of seconds from her saying that everything we just heard is absolutely right. So, Debra, you might want to continue

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your line of questioning, but be assured that there are extremely aggressive activities to try to get something into the House.

DR. LEONARD: So it seems that in the past with 1053 that the stakeholders that we've spoken with were some of the individuals or groups that were potentially blocking the introduction. Is it possible, since we've had conversations with them and I don't see any of these groups coming out and saying this should not be introduced -- I mean, even the Chamber has said, though, it does recognize that fear of potential discrimination may warrant a legislative solution. Is it possible for us to get statements from these groups so that those could be introduced with this document so that there's something in writing about their positions, or would they not at all be willing to do that?

MS. CARR: Well, one of the next steps that we wanted the committee to think about was to have a meeting of the stakeholders, bring them all together in one room. So I think we would like to continue to work with them, and we can certainly make that request of them to actually address the specific question of whether they would support the introduction of the Senate bill in the House. But these are sensitive negotiations that are going on in the Congress, and I'm sure there's a lot going on that we're not aware of. We do have to be careful of our role. We can't serve as a platform for negotiation of a bill, by any means.

But I think our effort has been trying to focus on finding out as much as we can and understanding as much as we can the concerns of the other stakeholders so that we can inform the Secretary about those, and in his discussions with the Congress he might be more fully briefed about those issues, and perhaps in discussions with Congress might be able to find ways of overcoming the differences and bringing everyone together.

So I think what we would probably want the committee to address is whether you would agree that we should have this request of a stakeholder meeting.

I think the other thing on the table, and perhaps the most important thing right now, is whether the committee would want to write a letter immediately to the Secretary. The stakeholder analysis, the legal analysis, is going to take a little more time. As Agnes indicated, we were hoping to have all three things together because it would be the more complete way to brief the Secretary. But given the momentum, as Francis said, on the House side and things that are going on there, it might make more sense for the committee to write another -- and this is a new Secretary, a new Congress. We've said these things before. It's a new bill. But it wouldn't hurt, I wouldn't think, for us to let this Secretary know right away what the concerns of this committee are, and also sending up the telephone book, as Ed said, that and along with it the DVD, which will be a very powerful way of demonstrating the concerns that the public and the patient community has about genetic discrimination.

DR. LEONARD: I agree that that should go forward. That's just my opinion, but I do think that that should be encouraged to be distributed to -- I mean have the Secretary distribute it to whoever the important people are in the House, and the committee chairs for sure, but if there are other key people.

DR. TUCKSON: By the way, just in terms of a specific answer to your other question about getting something in writing, I think what you have in the slides is about as close as we're going to get. They did write that in the sense that there was approval for those slides and the comments made there. So that was very careful, and I think you have something in writing, probably as

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much as you're going to be able to get, quite frankly. I'm sort of emphasizing that again because there's been an awful lot of conversation about it.

The committee is justifiably frustrated, as Francis and Ed and several of you have said. But just know that there's been, on your behalf, a lot of work going on to try to move this thing. People have not just been sort of sitting back since our last meeting.

The last comment was that there was a meeting. I don't know whether we know anything about it, but there was a conversation between the Chamber and some of those folks and the advocacy committee together within the last three weeks. I'm not sure if we know anything about that conversation and how it went, but I do know that they are meeting offline as well. So there's a lot happening here, and I guess I'll just leave it there.

MS. MASNY: Ed, did you have a comment?

DR. McCABE: Yes. I would just like to second Debra's support of a letter going to the Secretary. It's in the tradition of this committee and its predecessor committee, the SACGT, that it's been the first correspondence with each of the Secretaries that we have advised, and I think that we advise them on genetic non-discrimination, and I think it would be appropriate for us to keep with that tradition. But I would also, whatever we have together, I would send in support of that, and I would think we have all of the testimony of the folks. We have the ability to do the DVD with an excellent narrator in the person of our chair. So I would support that what we have in hand we send along with that letter.

DR. TUCKSON: What would you like specifically in terms of -- and we'll find out what the expectations are for the DVD to be produced, and I think Sarah needs to let us know what the timeline is. But with that information, give us some guidance around how soon you want this. Secondly, Ed, how specific do you want our letter to be regarding sort of saying something about the House?

DR. McCABE: Well, I would look back at the letters that we've used before, but I would emphasize the need to, in the appropriate jargon of inside the Beltway, pry it loose in the House. I'm sure there's a more appropriate art form to that language, but basically to try and move it forward. I'm sure that the Secretary understands the legislative process much better than I do, but Cindy's comment about the most expeditious way of moving it forward being to introduce 1053. I think we need to put the alternatives in there, but I would trust the staff and you, Reed, in terms of what the best language is. But I think we should be as detailed in terms of what we feel the steps are that the Secretary should take.

MS. MASNY: Melissa?

DR. FRIES: What were the lessons learned from 1053 in terms of its travels through the House? Because it seems to me -- did it even make it? Did it even show up anywhere? So it never even showed up anywhere. Obviously, that's the critical point. But then what would be the strategies that we have? Any other new information? Anybody else who could provide value on how to approach differently for different strategies? Clearly, you have a frontal approach, but you've got to get past that too.

MS. MASNY: Hunt?

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DR. WILLARD: I think that gets to one of the issues. Clearly, the Coalition is busy, the staff is busy, this committee is busy, and none of the questions have been questioning that. But when we first started this committee, we had a presentation from a legislative aide, if I remember, one of our first meetings, who was very helpful although frustrating, but helpful nonetheless in pointing out that this basically wasn't going anywhere, it was never going to get introduced to a committee, much less make it to the floor.

So my question is do we have any sense now that we have any friends anywhere in the House leadership where someone is tipping their hand saying, yes, this will make it, this is going to work its way through the process, or are we being stonewalled, as we were in the previous session, in which case we may have to think of a totally different strategy because business as usual isn't going to get us anywhere? Do we have any sense that we have somebody who is willing to take this on?

MS. MASNY: We have some comments from the audience.

Could you please give us your name?

MR. SWAIN: Yes. I'm Frank Swain, and I'm among the people who are working with the Coalition for Genetic Fairness. I very much appreciate this discussion. I'll try to make just a couple of remarks.

It's distracting but in our view not critical that the bill has not been introduced in the House yet. The bill could have been introduced -- last year's bill could have been introduced four weeks ago in the House, and our attempt to hold back those sponsors was purely to get a bill that is more acceptable to a broader range of people, including significant members of the House republican leadership so that the bill does not have the fate that it did in the last Congress of just going nowhere.

I would dearly like to have told the staff that we have Congressman X and Congresswoman Y as our key sponsors and they're going to put the bill in tomorrow. The Congress was on vacation last week and it might have happened had they not been on vacation. But we're hopeful that a bill will be introduced very quickly. We're hopeful that it will have bipartisan support, including support from some people that are significant and in the House republican leadership. But we're working on a moving target. We're trying to get people that will move this bill along constructively.

So it's certainly frustrating to you that there's not a bill, H.R. 1234, that you can talk about on your table this morning. If you're meeting, I can guarantee you that the bill will be introduced by the time of your next meeting. But more importantly, we're optimistic that not only will the bill be introduced but there will be constructive hearings scheduled and constructive discussion on the issues that the Chamber and others have raised that are of concern.

MS. MASNY: Joann, did you have any other further comment?

Kevin?

DR. FITZGERALD: Thank you. I was just wondering, in trying to follow the conversation, it appears to me anyway, as far as your action items are concerned, your first one says should the committee conduct a stakeholder meeting with the key stakeholders to further inform the report's analysis. Did you have any specific information in mind that you thought would be useful to

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have, because at least from the sounds of things, we're kind of in a Catch-22. Nobody knows exactly what the legal ramifications are going to be until a bill is introduced specifically. So that is sort of guesswork and speculation, and that can't do anything except kind of grind the whole process to a halt.

So is there anything else other than that sort of thing that the committee sees as necessary or beneficial? Otherwise, we'll just move with the action steps.

MS. MASNY: Very good point.

Ed?

DR. McCABE: Well, this is where we might use some help from people who know the process a lot better than we do, and that is it helpful for us to have a meeting of this group, or if those meetings are already going on in ways that are a little more sensitive to some of the issues, is that a better way to proceed? I'm all for a frontal assault, but ultimately I want the bill to go through. So whatever the best way for that to happen I think is the way we should go. So I would ask Cindy or maybe Mr. Swain whether us having such a meeting is a help or a hindrance.

MS. BERRY: I think it depends on timing. Certainly, the Secretary could have such a meeting, and if this is in fact a true administration priority and they really wanted to see something passed in this area, all the stakeholders would certainly listen to the Secretary, and the Secretary could reiterate the administration's position and attempt to get some sort of consensus. I'm not sure that a meeting before our committee would necessarily move the ball forward. I don't know that the parties would change their position any. We don't really have the ability to influence legislation and can't really influence legislation directly.

So my view would be a meeting before us wouldn't be too fruitful, but perhaps if the Secretary were interested and willing, he could bring all the stakeholders together and they could negotiate and work out the issues that are currently bollixing up the process.

One other thing that I did want to mention. I think what we can do to help move things forward in a constructive way would be to provide the Secretary with all of the information outlined in these slides, and then he can make use of it in the most appropriate way. My view also is that we could go ahead with a letter right away, but I would advocate keeping the other elements of the report together until all the elements are ready and then move it forward in one big piece, because I think the legal analysis is a key component, because there are so many groups saying that current law is adequate and protects the consumer. If, in fact, that is not the case, I'd like that to be part of the Secretary's report.

I wouldn't rush the DVD and send that up, and then send some other piece up, and then the legal analysis after that. To me, that's not as effective as having one big report that addresses all of the issues of contention, give that to the Secretary, and then he can make use of it, whether it's conveying the information to the committee chairmen, or the Coalition for Genetic Fairness could make use of that information and provide it to the key sponsors of the House bill whenever it's introduced, and they can make use of it on the Hill.

So I think one big compelling package would have greater impact than sending things up piecemeal, but that's no reason to withhold the letter. I think the letter could be the first piece.

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DR. TUCKSON: We're trying to get to closure, and our chairwoman here is giving us the signal. So, the details. One is the DVD. Just keep in mind that we can approve the script today, and you can do the DVD. That can get done in a couple of weeks, quick. The telephone book can be out in a couple of weeks. The legal analysis, Cindy, is a great point. I'm being informed that that's not going to be ready, and you've got to go through clearances and yadda, yadda, yadda, and it may not be until May or June for that. So as you make your recommendation, I just want to give you that data point. It may not be until May or June.

MS. MASNY: We would have one further comment from the audience, and then we're going to try to bring our recommendations to a vote.

MS. LEIB: Thank you. I'm Jennifer Leib. I work in Senator Kennedy's Health Policy Office on the HELP Committee staff. I think it's wonderful that in the last meeting and this meeting you've spent so much time focusing on this very important issue, and it was very exciting to see it move so quickly through the Senate earlier this month.

I think what would be really helpful is that we have an administration that in the last Congress and in this Congress has been very supportive of this legislation. However, other than giving that statement of administration policy, there really hasn't been any other efforts to help push this or move this legislation along in the House, and I think it would be really wonderful if you could recommend to Secretary Leavitt to really use the administration's strength to help move it through the House. We always turn to the agencies to help brief us and educate us about policies because they're the experts, so it would be great if Secretary Leavitt could look into having a briefing on the House side on the issue of genetic discrimination, showing the administration support, bringing constituents from the Chairmen's districts who have experienced genetic discrimination. I'm sure they're out there, either in the "Faces" book or just from people's personal experiences and practice in genetics.

So I think that would be a really helpful move, and even the briefing showing the DVD. I think those things need to happen very quickly as well, so I would encourage you to do that as soon as possible.

MS. MASNY: Thank you very much.

So I think we have a few things on the table right now that we could take a look at. First, I think the easiest one is just to get approval for the script for the DVD.

DR. McCABE: So moved.

PARTICIPANT: Second.

MS. MASNY: All in favor?

(Show of hands.)

MS. MASNY: Anyone opposed?

(No response.)

MS. MASNY: So we have the approval for the DVD to move forward.

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Then the second would be how we want to proceed with the report to the Secretary. Do we want to send up very quickly, then, the DVD along with all of the public comments and the testimony, and possibly also the administrative statement policy that was received, things that we have in place that we could send to the Secretary along with a letter? Actually, I guess the letter would be a separate recommendation.

DR. LEONARD: In addition, we could include stakeholder information, so we could include that summary. So really the only thing missing from this is the legal analysis, which needs all sorts of approvals and may hold us up. While I understand a complete package may be better, I think the timeliness of the rest of this is extremely important so it's out there and available to be used by whoever needs it. So I think a letter plus all the public comments, the DVD, and the stakeholder analysis that's been done should be sent.

DR. TUCKSON: Don't stop the flow, but I just want to make sure staff tells us exactly on the stakeholder analysis, apparently that can't go up. That takes a little bit of processing as well. Is that what you're saying?

MS. CARR: Well, we can certainly summarize the perspectives, as we have through the PowerPoint presentation. But we want to be very careful that we portray the stakeholder interests and concerns accurately. So we'll need to go back and forth a little bit, but we can certainly make it a very high priority and do our very best to make sure we can include some of that in the material that goes to the Secretary.

DR. TUCKSON: I think the spirit of the recommendation, Sarah -- and I just want to make sure again that we are all tracking here -- is to take the best that we can get. We have quite a lot of it done. Just give everybody one more chance quickly and get that out. But I think the clear mandate is forming that we want to get that done expeditiously. Whatever level that is, that's what it is.

MS. MASNY: Emily, and then Ed.

DR. WINN-DEEN: So I think what we can do to try and address Cindy's comments, because those are real legitimate comments, is we can inform the Secretary, send the letter, a summary letter -- "Dear Secretary, we still feel this way" -- and then enunciate to him that we have this part completed and it's coming right now, you got it with this letter. Then we have summaries of where things are with the various stakeholders. The third part, the legal analysis is underway, it's coming, and you can expect it in around, let's say, the June time frame, and then let him make the decision about does he want to wait until he has all his pieces of ammunition before he goes to talk to the House leadership, or does he want to act now.

It would arm him with all the ammunition that we have today and allow him to be responsive to whatever is happening between now and our June meeting, which would be our next opportunity to really approve something to move forward. I think it addresses Cindy's comments. He may feel that it is better to wait until he has all the pieces until he does something. That's his decision to make. We're here to advise him.

DR. TUCKSON: If I could make a friendly amendment to that. Two things. One is that we would encourage -- the legal analysis is being done by ad hoc members to this committee, ex officio. Excuse me. Those are the folks that are involved in this. So we would first make it explicit that we would ask our colleagues who are ex officio who are involved in that analysis to please move it forward. Secondly, what we can do also is in the body of the letter Emily put in to

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the Secretary urging the Secretary to ask those agencies to expedite the analysis, since they're in his government. So he has a relationship with those people, and we can ask him to do that as well.

DR. McCABE: From past experience with these letters, I know that if we did the letter alone, that can probably be prepared within the next week or two following this meeting. I would urge us to move that, and I was the one that proposed that we put whatever we had together. But also knowing Reed's schedule, I would guess the DVD is going to be a month or six weeks. They have to identify a production company and then do it.

How fast could these things move forward?

MS. CARR: We've actually already identified the producer of the DVD, and I think he's actually done a mock-up of a draft script. So I don't think technically it will take that long. The Chairman is going to be the narrator, and we can –

DR. TUCKSON: The Chairman is terrified of the wrath of the committee, so you can be doggone sure I'm not going to hold it up.

DR. McCABE: Well, as somebody who lives close to Hollywood –

(Laughter.)

DR. McCABE: -- I would argue that there is power in the people speaking and just looking and remembering those quotes. I also think that if it's going to take a while for the analysis, then I would urge us to try to have this out within the next three to four weeks, perhaps with the DVD that we could then send along as part of the final report. But I think that if anything is going to catch the attention of the Secretary within the next month or two, it's going to be that DVD. I understand the importance of the legislative analysis.

I would also ask -- I heard that there might need to be clearances regarding the legislative analysis, and I don't know if there's a possibility that that could come as a report of the committee rather than as a report from the various agencies, because if it comes as a report from the committee, then we don't need the clearances, because if we screw up, then it's our problem. So I would urge us to look and see if there's a way to do it as a report of the committee and avoid the clearances by the various agencies.

DR. TUCKSON: All right. I'm a little concerned about the time now, and I think we're going to have to move along. I think we have a very clear sense of the committee, so let us try to work this. The clear thing is, if I can summarize what I think you're telling us, to get this letter and the compilation of the testimony and the DVD and the urging of expedition on the legal analysis, and we'll ask about whether it can be done through us versus -- I still think it's going to be tough, but we can look at that offline. But to try to get all that in play right away.

If there is some reason that holds up any element, any of those, the DVD or any of that stuff, if there's some technical thing that we cannot foresee right now that will hold it up, then we need to use good judgment and get the letter in play so that we're moving and active. We will inform the committee if there's any glitch, but we'll go ahead and work that through, and we've got a sense of what the committee wants us to do, and we'll update you by email, if that's okay.

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DR. McCABE: I just wanted to add to what you said, Reed. I think Cindy's point that we should also include in that letter a request or an urging that the Secretary hold a meeting of the stakeholders, I think that will demonstrate to me as a member of this committee whether the administration is in fact supportive of this effort or whether we're just -- well, I think it will demonstrate whether they support this effort. Thank you.

DR. TUCKSON: Does anybody object to that?

DR. LEONARD: As well as including the recommendation or suggestion that the Secretary could have briefings for the House on the issue. I think we should make specific recommendations for actions that the Secretary could take with this information within the letter as well.

DR. TUCKSON: Let me thank our chairs, Agnes and Cindy. You've done a terrific job. And we thank the committee. Thank you very much to those who provided input to our work. So thank you. That was important, and we got good work done today.